



A checklist to a good transition



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Together for Short Lives is a UK wide charity that, together with our members, speaks out for all children and young people who are expected to have short lives. Together with everyone who provides care and support to these children and families we are here to help them have as fulfilling lives as possible and the very best care at the end of life. We can't change the diagnosis, but we can help children and families make the most of their time together.

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Introduction

As you get older it is very likely that you'll want to do different things, have a more active role in planning and to be treated differently. This is as relevant for your health and social care as it is for how you approach everyday life.

The move from children's to adult services is called **transition**. We believe that for your transition to be as smooth as possible and for you to settle into life well as an adult, you should know what to expect and what you can talk to your team of professionals about if things aren't going quite right.

Together for Short Lives published guidance for professionals supporting young people with complex health needs in 2014 and an accompanying guide for young people themselves in 2016. The guidance proposes five standards to be met at the various key stages of transition:

Standard 1	Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.
Standard 2	Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.
Standard 3	Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services. <i>This standard applies to all stages of the transition journey.</i>
Standard 4	Children's and adult services are actively working together to enable a smooth transition.
Standard 5	Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

Along with [NICE guidance on transition](#) published in 2016 and the [Scottish Principles of Good Transitions](#) from 2017, the standards help to ensure that every young person achieves a good transition.

This tool has been designed to help you assess what is going well and what things could be better.

How was it for you? We would love to know what you think of this checklist. Let us know by clicking [here](#).

How to use this checklist

1 Identify the phases of transition that are most relevant to you, using the guidance below:

Phase 1: Preparing for adulthood – Young person age 14+

[P6-7](#)

You have started talking about your plans for the future with teachers and care providers.

Phase 2: Preparing for moving on – Young person aged 14-18

[P8-9](#)

You have a transition plan in place and are moving towards transferring to adult services.

Phase 3 – Settling in to adult services – Young adult age 18+

[P10-11](#)

You've made the transfer to adult services and are continuing to receive any help and information you need to thrive in adulthood.



- 2 Read about the goals for the phase of transition you are experiencing – we've set these out as short, personalised statements.
- 3 There are various pop-outs to help explain what we mean by certain terms or to give examples in key areas.
- 4 Answer honestly whether you feel each of the statements are correct – you can say that the goals *are* being met, *aren't* being met, or are *partially* being met.
- 5 Add up your answers for each phase individually – you'll find you've answered 'mainly yes', 'mainly no' or 'partially'. When you've read the guidance about next steps to take, talk to your care provider about any areas that are causing you concern.
- 6 We want you to be achieving the very best transition possible – if you feel you still need more guidance on how to improve any phase of your transition you can contact our free helpline on 0808 8088 100.



Together for Families Helpline
10am-4pm, Monday-Friday

0808 8088 100

info@togetherforshortlives.org.uk

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Name:

Date of birth:

Phase 1: Preparing for adulthood – Young person age 14+

You can answer these questions when you have started talking about your plans for the future with teachers and care providers.

- We believe:
- Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services.
 - Families should be supported to prepare for their changing role.

Goals		Are these goals being met?		
		Yes	No	Partially
A1	I have talked to my parents, teachers and others involved in my care about my plans for the next few years.			
A2	I have a named worker who I trust and who I can talk to about what I want to do.			
A3	I know what to expect as I get older, move on in my education and have support from adult services.			
A4	I know what type of care and support options will be available when I'm older.			
A5	I have discussed what care I may expect if my health gets worse at any time in the next few years.			
A6	I know how to remain involved in matters concerning my transition.			
A7	I am aware of assessments that I may need to have.			
A8	I know what peer support (support from other young people who have experience of transition) and advocacy (support from someone independent from children's or adult services who can represent your interests) is available throughout my transition.			
A9	I have been given information about how funding for my carers may change as I get older.			
A10	My parents are clear about their role in supporting me to make decisions about my future.			

Name:

Date of birth:

Mainly 'yes'	Mainly 'no'	'Partially'
<p>You and your family have been given the opportunity to talk to those around you about your needs and wishes for the future. A range of people have been involved and they know what role they must play in supporting you.</p>	<p>It is important that transition planning starts as early as possible. Some of the things you may want to do will take time to put in place. Ask your teachers or care team to call a meeting to discuss what options are available to you across all services.</p>	<p>If you feel uncertain about what changes to expect over the next few years, make sure you have a transition plan in place that is reviewed and fully explained to you and your family. Do ask as many questions as necessary – it's your plan after all!</p>

Notes

Name:

Date of birth:

Phase 2: Preparing for moving on – Young person aged 14-18

These questions should be answered once you have a transition plan in place and are moving towards transferring to adult services.

- We believe:
- Every young person should be supported to plan proactively for their future.
 - They should be involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.
 - Every young person should have an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.
 - Children's and adult services should be actively working together to enable a smooth transition.

Goals		Are these goals being met?		
		Yes	No	Partially
B1	I am happy that my transition plan reflects what's important to me, what I feel I can do and what I want to be able to do in the future.			
B2	I regularly review my plan with my named worker as my situation changes to make sure it's still right for me.			
B3	I am being helped to identify services and opportunities that are suitable for me as I get older.			
B4	I have discussed ways I can be introduced and become familiar with any new settings or services before I start using them.			
B5	I have a care plan in place and a summary profile all about my care preferences and interests to share with new carers and agencies.			
B6	I have thought about my care preferences should my health deteriorate and have shared these so people know my wishes should I be too poorly to communicate			
B7	I am being encouraged to take on more responsibility in managing my pain and other symptoms.			
B8	I feel the individual needs of my whole family are being recognised and supported.			
B9	I feel that children's and adult services are working well together, enabling me to live my life to the full.			
B10	I have opportunities to ask questions about my future and feel prepared for the move to adult services.			

Name:

Date of birth:

Mainly 'yes'	Mainly 'no'	'Partially'
<p>Everything is going according to your transition plan and you are being encouraged to think about what you may want to do or where you might want to live when you become an adult. You and your family are prepared for changes to the services and support you may receive in times of both stable and deteriorating health.</p>	<p>If you feel unprepared for the changes you are likely to face over the next few years, request that you and your family are given the opportunity to discuss your transition plan with all agencies involved. Reading <i>Moving to Adult Services; what to expect</i> may help determine the priority areas for you to raise. Do seek independent support if necessary. Your named worker should be able to identify an advocate to support you.</p>	<p>Your situation and plans for the future are likely to change over time and it is important to review your plan and take time to consider the various options that may be available. Insist that you are given the opportunity to update your plan to reflect these changes. It is important to capture discussions you have had with those closest to you about your wishes should your health deteriorate.</p>

Notes

Name:

Date of birth:

Phase 3 – Settling into adult services – Young adult age 18+

Support doesn't stop once you've made the transfer to adult services and you should continue to receive the help and information you need to thrive in adulthood.

We believe:

- Every young person should be supported in adult services with a multi-agency team fully engaged in facilitating care and support.
- The young person and their family should be equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

Goals		Are these goals being met?		
		Yes	No	Partially
C1	I feel that the care and support provided by all the agencies is well co-ordinated.			
C2	I am building good relationships with new healthcare professionals from adult services, including my GP.			
C3	I am able to access services that address my needs and that are appropriate for my age and understanding.			
C4	I know where to go for information or who to go to for advice.			
C5	I have access to an advocate, offering independent support and representing my interests if needed.			
C6	I know who my lead doctor is, to take responsibility for me when I attend adult clinics for my condition or am admitted to hospital.			
C7	I am aware of any options available to allow my parents/carers to have respite from their caring role.			
C8	I am given opportunities to socialise with friends and maintain hobbies and other interests.			
C9	I am proactive in ensuring that my care plans are updated and reflect my care needs and wishes.			
C10	My parents are happy with the level of involvement they have in helping me make decisions.			

Name:

Date of birth:

Mainly 'yes'	Mainly 'no'	'Partially'
You feel able to live life as an adult, as independently as you wish. You are well supported by services and able to realise the ambitions you have.	If your health and social care needs are not being met, it is unlikely that you will be able to access any other opportunities that may be available to you. Request a reassessment of your care needs and ensure that your care plan is adequately supported by the responsible agencies.	Ask for a review of your care plan and highlight areas where you feel there are gaps in provision. Ensure that your GP is aware of the impact that any gaps may be having on you and your family's health and emotional wellbeing. If you need help knowing where to turn, call 0808 8088 100.

Notes